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Barriers and opportunities for participation in health policy decision-making by civil society groups organised for cancer in Chile: a qualitative study

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ABSTRACT

Background: Social participation, a principle that has guided health reform processes globally, presents diverse barriers according to the political and social context, obstructing its effective exercise. This study examines the perceptions of various stakeholders regarding the barriers and opportunities for social participation in decision-making processes within Chile's National Cancer Plan and Law framework.

Methods: A qualitative multiple-case study design (cases: politicians, academics, decision-makers, organisations) was employed. Twenty-eight semi-structured online interviews were conducted with stakeholders involved in the planning and implementation of the National Cancer Plan and Law, as well as with its beneficiaries. Thematic analysis was carried out through the analytical framework method, a systematic and flexible approach to analysing qualitative data. Approved by the Scientific Ethics Committee of the Universidad del Desarrollo, Chile.

Results: The main perceived barriers were classified into four areas: a) disarticulation of civil society organisations, b) lack of validation of organisations in decision-making processes, c) lack of access to information and d) lack of tools for the professionalisation of organisations. Opportunities for action are proposed that involve joint actions from all actors in a paradigm shift exercise on social participation in health, and the degree of involvement that all stakeholders should have to achieve more significant equity in participation.

Conclusions: The results suggest that persistent barriers to effective participation exist, primarily due to power imbalances and the dominance of biomedical perspectives. The findings emphasise the importance of authorities and decision-makers acknowledging the

value of knowledge from civil society to encourage collaborative and sustained work that transcends individual leaders and governments.

Keywords: Patient Participation, Social Participation, Decision-making, Neoplasms, Qualitative Research.

Background

Social participation in health has been a guiding principle in the modernisation and reform of health systems worldwide, particularly since the Declaration of Alma Ata (1,2). The Pan American Health Organisation (PAHO) has defined it as 'collective actions through which civil society and organised communities can influence the organisation, social control, management and oversight of health institutions and the health system as a whole' (3). This concept is closely related to the principles and purposes of democracy, as both are based on the idea that sovereignty should come from the people and involve their active participation (4–6). In participatory and deliberative democratic models, public decisions gain legitimacy when they incorporate the voices of diverse stakeholders (7). Therefore, social participation in health contributes to the effectiveness and contextual relevance of policies and strengthens the democratic process by redistributing power, challenging technocratic monopolies on expertise, and opening up opportunities for alternative forms of knowledge, such as those based on lived experience (8,9).

For social participation to be effective or meaningful, it must go beyond formal consultation and ensure that civil society actors can influence the design, implementation and evaluation of public policies. This requires inclusive, sustained and accountable dialogue processes that mitigate power imbalances (10–12). Therefore, it should be understood as a continuous and

dynamic process in which participation forms the basis of social transformation, rather than merely a temporary contribution to a project (13,14). However, various barriers to effective social participation have been identified. The lack of a unified definition of social participation is one such barrier, as the meaning and interpretation of the concept depend on each country's social and political environment (3,15,16). Participation occurs through the power relations and imbalances inherent in each context, often marked by ambiguities and contradictions (11,13).

Consequently, social participation in health usually involves conflict due to political and ideological disagreements, which can be crucial to achieving significant change. However, for conflict to be productive, participation instances need to anticipate and manage power imbalances and struggles (13). Power struggles of this kind are unfolding in almost all countries within the biomedical paradigm, characterised by biologism, pragmatism, and individualism. It subordinates or excludes the psychological and sociocultural dimensions of health and disease processes in relation to the biological dimension, thereby diminishing the legitimacy and value of diverse forms of knowledge, such as experiential knowledge, in health decision-making (2,17,18). As participatory processes are epistemic by nature, they require the recognition of different forms of knowledge (19,20). This helps to address epistemic injustice and challenge the dominance of technocratic and biomedical perspectives in health. Moreover, studies show that co-producing health interventions through the deliberate combination of theoretical and community-based knowledge results in more effective, contextually appropriate responses (21,22). Therefore, valuing and incorporating multiple forms of knowledge is not only ethically necessary, but also strategically essential for democratising public health decision-making.

Advancing social participation also requires attention to equity, as participatory mechanisms not only confer legitimacy on health policies but also determine which voices shape decisions affecting population health and well-being. Inequity in health is expressed not only through differential outcomes but also through unequal access to spaces where health policies are deliberated and decided (23,24). This is particularly salient in cancer, where social determinants create systematic patterns of vulnerability and higher disease burden (25–27). While participatory processes can challenge these structural inequalities by recognising diverse forms of knowledge and redistributing decision-making power, they risk perpetuating exclusion when designed around technocratic frameworks that assume resources, knowledge, and capacities not equally available to affected populations (28).

In Chile, social participation in health policy has been implemented, culminating in the 2005 health reform process. This reform did not establish mechanisms for effective social participation, since these were mainly consultative (29), leaving citizens out of the decision-making process (1). It is important to note that the concept of social participation underwent a transformation in the 1990s due to the validation of a less significant role for the state and the consolidation of market logic and models in the health sector (1,30,31). This framed social participation within a new dynamic between consumers and providers, in which the former's demands and needs had to be met by the latter. This logic has affected instances of social participation since then (1,32).

Chile has had significant mobilisation and civic participation in recent decades regarding cancer needs (33). In 2018, the country developed the National Cancer Plan (NCP) and, responding to civil society demand, the National Cancer Law (NCL) in 2020, which provided a framework for the NCP, ensuring its proper implementation and long-term operation (34–

36). The drafting of the NCL involved a method that represents the first experience of its kind, where the civil society gave their input on each law article through a public consultation platform (34,36). The drafting of the NCL was approved in 2020 and includes platforms for citizen participation, such as the National Cancer Commission (NCC), whose objective is to advise the Ministry of Health in formulating policies, scientific research and implementing cancer strategies (35).

Against this backdrop of significant normative and institutional development of social participation in health in Chile, particularly in relation to cancer policy, important challenges remain regarding the effective implementation of participatory frameworks and the translation of participation into meaningful influence on decision-making (3,37,38). Despite the growing body of literature on social participation in Chile and Latin America, there is still limited empirical research that considers these challenges from the perspective of multiple stakeholders and incorporates proposals made by those involved. Drawing on the experience of the National Cancer Plan (NCP) and the National Cancer Law (NCL), this study examines the views of civil society representatives, policymakers, academics and politicians on the involvement of organised civil society groups in the decision-making process for cancer-related health policies. The analysis identifies perceived barriers to effective participation, as well as opportunities and proposals to strengthen participatory processes. In doing so, it advances knowledge by providing an empirically grounded, multi-actor analysis of social participation in cancer policy in Chile.

Methods

This section follows the consolidated criteria for reporting qualitative studies (COREQ) 32-item checklist, available in supplementary material.

Study design

An exploratory and descriptive qualitative study was conducted using a multiple-case study design. This involves exploring and collecting information from different cases to gain an in-depth understanding of the research topic (39,40). The perception of the role of organised groups in decision-making processes was addressed from the perspective of different actors (organisational leaders, academics, decision-makers, and politicians). Each of these actors represented a case, thus generating a variety of cases for the study.

Recruitment and participant selection

The sample of participants was based on theoretical and feasibility criteria. A profile of participants related to cancer or the NCP and NCL was established. The inclusion criteria were: i) being a member of a civil society organisation working on cancer (registered or not in the National Registry of Organisations related to Health), ii) being a decision-maker in the framework of the NCP and NCL, iii) being a politician with work related to the NCP and NCL, iv) being an academic dedicated to cancer. Participants had to be at least 18 years old and have access to the Internet to participate in the digital interviews. Members of civil society organisations with less than one year of activity were excluded. This criterion was established to ensure that organisations had experience of interacting with institutional stakeholders or engaging in health-related advocacy. Organisations with less than one year

of activity would not have been active during the participatory processes associated with the NCP and NCL.

To recruit and select participants, health authorities who were decision-makers, politicians involved in the NCP and NCL, and academics who work on cancer were invited by e-mail. Five decision-makers, three politicians and four academics were invited, all agreeing to participate. The group of academics included professionals from the fields of epidemiology, medicine, health economics and psycho-oncology. Three of them were affiliated with institutions located in the central region of Chile, while one participant was affiliated with an international academic institution.

Regarding civil society, the National Registry of Health-related Organisations (NRO), which is publicly available, was reviewed. From this registry, we invited by e-mail organisations from different macrozones of the country (North, Center and South). At the same time, we searched through websites and social networks for other organisations related to cancer that were not registered in the NRO. In this way, out of 18 invitations to groups in the NRO, 8 did not respond to the invitation and 10 accepted participation in the study. Concerning unregistered organisations, out of 10 invitations, 4 did not answer and 6 accepted. Representatives from civil society organizations included both professionals and individuals whose involvement stemmed from lived experience with cancer as patients, survivors, or caregivers.

It is important to note that the majority of participants were women, particularly among the civil society representatives. This may reflect existing gender dynamics in the field of cancer advocacy in Chile. A contributing factor may be that most civil society organisations focused

on cancer have been formed around female-specific or childhood cancers, in which women often assume leadership roles. This gendered pattern emerged naturally from the recruitment process and is consistent with emerging literature on gender and participation in cancer advocacy (41).

Regarding educational levels, all politicians, decision-makers, academics, and registered civil society representatives had completed higher education. Among unregistered representatives, educational levels ranged from secondary to higher education. The activities varied systematically, with registered organisations predominantly engaging in policy advocacy and educational activities, and unregistered organisations primarily focusing on direct patient support. The activities of politicians included legislation and health policy advocacy, while the roles of decision-makers encompassed public health administration and health system governance. Academics, meanwhile, engaged in research, teaching and policy advisory work.

The details of the study participants by macro zone are presented in Table 1.

Table 1. Study participants.

Data collection

Semi-structured individual interviews were conducted between July and September 2023, using a flexible interview script that addressed the dimensions of interest of the study. The interview guide was prepared by FV and CC and addressed the following dimensions: i) perception of citizen participation in the decision-making processes of the NCP and NCL, ii) perception of barriers and opportunities for action for effective citizen participation, and iii) recommendations to enhance citizen participation in health in Chile.

The interviews were conducted by BC, AO, FV, AR, and CC, who had previously trained and experienced interviewing people with cancer. The interviews were conducted and recorded virtually through Zoom, averaging 45 minutes each. To guarantee the confidentiality of the interview, a Zoom account exclusive to the principal investigator was used. Each interview was recorded for transcription following consent from the participant. After conducting twenty-four interviews, the research team held preliminary analysis meetings to assess thematic saturation. This is defined as the point at which no new themes or sub-themes relevant to the study objectives and key analytical dimensions (barriers, opportunities and recommendations) emerge (42,43). Three researchers (FV, AR and CC) independently reviewed the codes generated during the initial analysis and concluded that the final interviews had deepened existing categories without introducing new themes. This assessment was subsequently discussed and validated by the full research team (BC, AO, FV, AR, CC and ME), leading them to conclude that additional interviews were unlikely to provide new thematic insights. Consequently, it was determined that there was no need to recruit further participants.

Data analysis

Interview recordings were transcribed verbatim into a Microsoft Word document, and each transcript was checked for accuracy against the original audio. Building on the preliminary analytical work conducted during data collection, the analysis was carried out manually, without the use of qualitative data analysis software. FV, AR, and CC independently conducted a thematic analysis using a deductive–inductive approach.

An initial codebook and analytical matrix were created in a Microsoft Word document based on the guiding dimensions of the interview guide: perceptions of participation, barriers,

opportunities and recommendations. Relevant excerpts from each interview were organised within the matrix, using the framework method (44). As analysis progressed, new categories and codes emerging from participants' narratives were incorporated inductively into the matrix (Supplementary File 4). Each researcher developed an initial version of the analytical matrix through this process.

The individual matrices and codebooks were subsequently reviewed in iterative team meetings involving FV, AR, CC, AO, BC, and ME. During this cross-review process, coding decisions and category definitions were compared and discrepancies were discussed by examining specific text fragments and referring to the analytical framework until consensus was reached. This resulted in a final matrix incorporating both predefined and emergent themes.

The verbatim quotes included in this article were translated from Spanish by a native English speaker and reviewed by the authors to ensure that they accurately captured the original meaning.

Qualitative scientific rigour

The study applied the following rigorous criteria: triangulation and theoretical-methodological adequacy (45,46). In triangulation, the analysis was contrasted among the researchers of the team, who have different backgrounds and experiences. The research team comprised two social anthropologists, one social epidemiologist, one sociologist, one health economist, and one physiotherapist. This helps to reduce bias in interpretation. There was also triangulation between informants, taking into account the different perspectives and contexts of the interviewees. Regarding theoretical-methodological adequacy, in the first

phase of the study, we checked whether the research problem was logically related to the methodology, design and theory, thus ensuring the project's coherence.

Ethical considerations

The study considered Chilean laws to protect participants in health research. It was guided by the universal principles of scientific research (respect, beneficence, non-maleficence and justice) in its formulation and application. The research team guaranteed that the participants received all the information about the study by providing an information sheet, ensuring their understanding and consequent voluntary participation. A digital informed consent form was signed through the encrypted platform Alchemer, ensuring the security of the information. Codes were assigned to all of them to safeguard the confidentiality of the participants. The study was approved by the accredited Scientific Ethical Committee of the Universidad del Desarrollo (#2023-60).

RESULTS

Barriers to citizen participation

The interviewees identified several barriers to citizen participation in cancer health decision-making. These are organised into four dimensions: a) organisation of civil society, b) lack of validation of organisations in the decision-making process, c) access to information, and d) professionalisation of civil society organisations.

Organisation of Civil Society

The first obstacle is related to the way civil society is organised. Groups are fragmented and carry out actions independently according to the type of cancer they represent. This leads to duplication of efforts or failure to reach a consensus on shared objectives and actions to work

with the Ministry of Health. Politicians and decision-makers observe that this makes it challenging to prioritise actions and proposals.

> *"I find that it has been less active, less united and therefore less participatory (...) in the end we make individual efforts that do not necessarily move the needle in health decision-making." (E1, Registered organisation)*

Representatives of organisations observe that each group's different work modes prevent an organic articulation between them. They note that some are committed to updating knowledge, language and methodologies according to the decision-making platforms to generate proposals. In contrast, others focus on demands to the authorities based on testimonies of patients' cases. Politicians, academics and decision-makers also note this difference.

Another divergence between organisations is related to the mission and vision of the groups. Some organisations are interested in participating in decision-making committees and influencing public policies, while others aim to support patients and those closest to them directly. It is noted that only a minority of organisations are interested in formal participation in public policy, resulting in a lower level of civil society participation in high-level health decision-making.

> *"The different realities that we have with the patients' organisations…some work with a perspective that is a little bit more from the point of view of always denouncing, as if they were always passing the bill. Others work more from the perspective of, well, how do we take charge? how do we go about proposing? how do we go about controlling? And I think that we patients still have a lot to do and that we really need to have the patient at the centre." (E1, Unregistered organisation)*

Some participants believe that social participation in Chile has declined recently. They argue that citizens are disillusioned with participatory processes because they are not sustained over

time. Additionally, these groups believe that there has been no progress in addressing the needs they have raised within the cancer health policy-making process. Due to the current disarticulation between groups, interviewees from organisations, academics, decision-makers and politics, observe that some people and organisations do not feel represented by those leading the social participation forums in the health field.

Lack of validation of organisations in the decision-making process

Another perceived barrier is the groups' lack of validation as relevant actors in cancer health policy decision-making. According to representatives of organisations, this is reflected in the fact that they are invited to the decision-making processes but are not formally involved in the final decisions. Other participants (politicians, decision-makers, and academics) agree that the health authority gives greater weight to the clinical view, especially the opinion of physicians.

> *"As we have not been validated as protagonists and as relevant actors, we are always destined to a second or third place or we are more secondary, more tertiary" (E2, Registered organisation).*
>
> *"(...) and I tell you more, still neither the health authorities, nor the scientific, nor all the actors involved have understood how much patient organisations can be a source of innovation and added value (...)." (E2, Academic)*
>
> *"(...) We are in such a hierarchical system, where what matters many times is the medical opinion, the opinion of the medical scientific society, only white coats making decisions." (E4, Decision-maker)*

An additional element detrimental to organisations' ability to consolidate themselves as valid actors before authorities and decision-makers is when they form partnerships with politicians and the pharmaceutical industry. These relationships raise suspicions about the actions of civil society organisations, as they may be manipulated for the benefit of third parties. This

creates mistrust between the various actors, which slows down the processes of social participation in high-level health decision-making.

> *"These two notions coexist in the work of the health authority, of the ministry (...) There are people within the ministry who are influenced by this idea that the organisations are absolutely captured; all or many of them or those that make the most noise are captured by the industry. On the other hand, there are people who say, well, taking that into account, we have to work for participation, and we have to include the patients independently of this, etc. Therefore, there is a conflict there that I think creates obstacles for the health authority to be able to advance effectively in citizen participation". (E1, Academic)*

Access to information

Respondents identified a third barrier related to access to information. Decision-makers point out that the Ministry of Health does not always provide information to civil society, indicating that this is due to the authority's concern to protect sensitive information. This means that the information does not reach the representatives participating in the National Cancer Commission in time. Therefore, the information does not get to the base of the organisations in a fluid and consistent manner, and the legitimacy of participants and the work being done is questioned.

> *"Permanently we find ourselves as a commission that we ask for information, and it does not arrive, it arrives late, that has been a permanent difficulty, then it also happens to us from the side of the commission that we meet with the bases, and we agree to deliver certain information, but since it is not delivered to the representatives of the National Cancer Commission, you lose validity, legitimacy with the bases" (E2, Politician).*

Professionalisation of civil society organisations

The absence of formal training to professionalise the organisations was also identified as a barrier. All respondents felt that having at least health systems, advocacy, and ethics training would be helpful. Health systems and advocacy training would allow the organisations to

focus on interventions and actions that move away from individual issues and towards collaborative public health work. Ethics training would contribute to good information management and the groups' efforts to meet transparency requirements and standards.

> *"You need a little bit of training in the health area, a little bit, in other words, to understand how the health care system works (...)." (E1, Registered organisation)*
>
> *"Yes, of course, all advocacy actions require a series of competencies, they require a series of planning, and that is what patient organisations need to be trained in (...)." (E2, Academic)*
>
> *"Then there are ethical decisions that one is making that, in some way, hopefully there is a training course to tell you this is done this way, or this is not done. But it happens to us that there are some organisations that do [share information] and finally impact or harm those people unnecessarily because you don't have the solution." (E9, Registered organisation)*

Participants from the agrupations also indicated that organisations should be advised of the requirements that must be met to participate in decision-making committees. This relates to the elements necessary to consolidate the organisation, such as defining its mission, vision, legal aspects, accounting, etc. The interviewees, especially academics, pointed out that the organisations should also work on their internal representativeness, developing systems for electing and renewing leaders based on transparent criteria so that each group goes beyond its founder.

> *"(...) there should be facilitating mechanisms for the civil social organisation, from how to legally establish it, to accounting aspects, to defining the mission, which I think is a big problem, since many groups do not have a mission (...) when they had all the intention of doing important things and then it starts to unravel and they have a half deformed thing". (E5, Registered organisation)*
>
> *"The work of internal representativeness, that is missing a lot, that is to say that those who are going to lead and with this I am also talking about thinking that the organisation is not mine, (...) but thinking that the organisation has to transcend the person who founded it or the president or the board of directors that has been there for so many years, they should have transparent elections, renewal, training of new leaders who will replace the current ones, that is missing a little bit (...)." (E2, Academic)*

Analysis of the perceptions of different stakeholder groups reveals significant convergence in the identification of the main barriers to social participation in cancer-related decision-making. All stakeholders agree that organisational fragmentation, a lack of institutional validation, restricted access to information, and limited professionalisation of civil society organisations hinder their effective involvement in public policy. However, these barriers are perceived differently. Civil society organisations are more aware of the obstacles related to their organisation, identifying different visions and approaches to work as limitations to their coordination. In contrast, political actors and decision-makers view this diversity as a challenge to collective action in decision-making spaces. Regarding the lack of validation and professionalisation, civil society organisations emphasise their exclusion from decision-making processes and the devaluation of their experiential knowledge. While politicians and decision-makers broadly recognise this issue, academics raise a different concern: a lack of trust in civil society organisations that have links with political figures or the pharmaceutical industry, which calls their independence into question. Finally, regarding access to information, both organisations and politicians note that delays in receiving key information affect timely action. However, decision-makers cite the need to safeguard sensitive information as a constraint, which contrasts with this perception. These distinctions highlight the importance of recognising the structural and cultural dimensions that shape participation in health policy.

Opportunities and recommendations for participation

The opportunities and recommendations put forward by the participants are presented concerning the barriers they identified, grouped in three dimensions: a) organisation of civil

society, b) lack of validation of organisations in the decision-making process and professionalisation of civil society organisations, and c) access to information.

Organisation of civil society

Respondents see an essential opportunity to promote joint and articulated work among organisations. They recommend the creation of working instances where groups from all areas of the country can share their concerns and develop common objectives. It is suggested that these forums should be constant over time and allow for a collaborative prioritisation of issues to be presented in decision-making spaces. It is also essential that the groups work on existing initiatives to avoid duplication and improve cooperation. Another recommendation is to disseminate critical information for civil society in a sustained manner over time.

> *"A system of prioritisation and channelling of concerns from civil society must be made, because, having a board with many people who have different opinions, in the end, everyone fights for what is convenient for them and that is not the idea, because, in the end, that does not benefit everyone, it benefits only a small group, so, in the end, it must be channelled." (E6, Registered organisation)*

Lack of validation of organisations in the decision-making process and professionalisation of civil society organisations

Regarding the lack of training for the professionalisation of groups, the interviewees identified several opportunities. The first element is to carry out a census of organisations at the national level to ensure that growing organisations receive help in their formation from long-established organisations and other actors such as academics and state officials, among others. In this regard, the academics interviewed believe they can contribute to forming and training organisations in advocacy, ethics and the health system. Likewise, it is felt that academics could generate information on the functioning of the organisations and their role in Chile and other countries.

"One recommendation to the commission is to formalise the organisations that are not there, to strengthen the space for representation and participation, and this has a concrete expression in adding organisations that could not participate at the time and the new ones that are being generated." (E2, Politician)

"(...) it is up to the academic world to generate educational spaces at least, or to help perhaps not in resources, but to help in strategies that allow first to define the reality (...), and in fact, from the academy to map what is there, to define what in other models in other countries is the role of patient organisations and foundations, to define what the problems are and to propose solutions, that is up to the academic world. And it is up to the academic world to recognise, describe and propose strategies for better functioning." (E3, Academic)

Also, it is pointed out that not all the responsibility for continuous training should be charged to the organisations but that all the actors (politicians, academics and decision-makers) should be trained together to promote real collaborative work that does not depend on governmental changes. This would contribute to constructing spaces of greater horizontality and validating the different stakeholders in the high-level decision-making processes of the health authority on cancer in Chile.

The interviewees also pointed out that the professionalisation of the organisations contributes to changing the vision that certain authorities and decision-makers have about the role and social value of the organisations. They comment that there is a perception from the State that organisations only demand and protest, which is why the authorities concentrate on avoiding conflicts or public protests instead of generating binding instances of participation.

"There are few who manage to understand that you have to work together, but in the end what you first think is that the only thing they are going to do is to bother, to demand, to protest, to knock on the door, and that is not it, I believe that it is enough that there is a natural leadership on both sides, that you can work together, that you feel that both are a contribution and not that they are enemies, which is what happens with the organisations." (E3, Politician)

"Then probably the only real interest that the Ministry has in the patient groups is for them not to generate tension in the public environment about what is happening, that is

> *what happens, (...) in the end the only thing that matters to them is that there is no strike or article in the newspaper (...)." (E3, Academic)*

Academics see an opportunity for action to change the perception of state authorities and decision-makers. Academia can generate research that makes the value of citizen participation visible. At the same time, they can act as facilitators of conversations between civil society and the authorities, focusing on the exchange of concrete proposals for the country.

> *"(...) then promote conversation, be aware of the limitations of the scenario and propose, we do not only, it is something that we do not only motivate the leaders, you do not only go to complain, you have many ideas, many proposals, go to propose, be part of the solution, be part of the solution, because we must also be aware that our health system is living very, very complex times (...) then we do have to make decisions that are difficult so that they see in the patient organisation an ally (...)." (E2, Academic)*

Respondents also highlighted another aspect that needs to be addressed: the tension between authorities and patient organisations due to their links with the pharmaceutical industry. To this end, they suggest creating a regulatory framework of best practices and transparency mechanisms for all parties involved. Thus, constant accountability to society could be promoted, and potential conflicts of interest between these social actors could be disclosed.

Access to information

Regarding barriers to access to information, politicians and decision-makers recognise that information on the progress of the Cancer Law should reach civil society organisations on time so that they can intervene in discussions on pending aspects of the Law's implementation. To this end, they suggest establishing a strategic work-line of citizen participation in the NCP. This should consider territorial differences in the country to decentralise decision-making processes and instances of participation. Concretely, it proposes the creation of constant work instances in each region to incorporate the reality of each place.

> *"Unfortunately, I think there should be a unit specifically to work with that [in the National Cancer Plan]. Because of course, for the rest of the strategic line there is the local technical council, the ministerial referents, but we are all professionals." (E1, Decision-maker)*

> *"There is no fixed calendar, for example, of meetings or a bulletin that reaches us all, and I think that leaves many people out and also, this is centralised in Santiago, in the reality that we have in the central zone, more than what happens in the extreme zones for example of Chile, which are super different realities, I feel that there we are behind." (E1, Unregistered organisation)*

In this regard, it is recommended that the NCC strengthen its work in the field, act as a coordinating entity between different actors and territories, and follow up on the implementation and fulfilment of the Plan. Finally, the need to create greater trust between civil society, government institutions, and their authorities through establishing transparent communication mechanisms and greater participation is highlighted.

> *"Nobody believes anymore in what has been created because nothing works, so the way to maintain trust is to comply at least with what the laws say, and by that, I mean (...) to improve those instances of participation and transparency." (E1, Politician)*

A summary of the barriers, opportunities and recommendations is presented in Table 2.

Table 2. Barriers, opportunities and recommendations for participation.

DISCUSSION

The findings of this study confirm and build upon previous literature on social participation in health, highlighting that one of the main barriers lies in the persistent ambiguity surrounding the concept itself (16). This ambiguity gives rise to several challenges that hinder effective social participation in decision-making processes. These challenges include: (a) fragmentation and differing orientations among civil society organisations, (b) limited institutional validation of these organisations by health authorities, (c) insufficient training and resources for their professionalisation, and (d) restricted and often delayed access to

relevant information. By examining these barriers from the perspectives of multiple stakeholder groups, this study sheds light on the interplay between structural and relational factors that shape participation in health policy processes.

These results must also be considered in the context of equity, as they demonstrate how participatory mechanisms can perpetuate, rather than challenge, structural inequalities in cancer policy. Participation designed around technocratic frameworks that assume organisational capacity, technical fluency or the ability to engage in centralised decision-making spaces systematically excludes those most affected by cancer inequities, such as rural communities, lower socioeconomic groups and those with limited formal education. These populations bear a disproportionate cancer burden due to social determinants yet have the least access to spaces where cancer policies are deliberated and decided (26,27). Thus, addressing these barriers is not merely a matter of improving participatory efficiency but of advancing health equity by redistributing decision-making power.

Equity concerns are evident in each of the identified barriers, such as the organisational fragmentation of civil society groups. While some organisations aim to build technical knowledge and influence public policy development, others focus on providing direct support or voicing specific demands relating to the types of cancer they represent. This fragmentation mirrors the broader consumer-provider dynamic in Chilean health policy and hinders coordination and the ability to exert collective influence (1,32). This is consistent with regional and international findings that fragmented civil society limits the ability to launch joint advocacy campaigns or exert political pressure (47–49).

In this context, an asymmetry of power exists between the authorities and civil society organisations, reflected in unequal access to information and the prioritisation of the

biomedical-clinical vision over other types of knowledge. This is characteristic of what has been defined as the predominance of the Hegemonic Medical Model (17), whose immobility restricts the development of new elements for deliberative processes and dialogue between different epistemologies (13,18,50,51). Addressing this requires epistemic justice: recognising civil society as legitimate knowledge-producers whose experiential knowledge must carry real weight in decision-making, not merely symbolic inclusion (52,53). Recent literature documents that experiential knowledge has been systematically devalued in favor of clinical and academic knowledge (53,54). For participation to be transformative, it must move toward co-production of knowledge, collaborative processes where experiential, practice-based, and research knowledge are equally valued and integrated (55).

These asymmetries are embedded within the formal participatory structures established by Chile's cancer policy framework. The National Cancer Commission, structured advisory councils, designed to incorporate civil society voices, presuppose specific capacities: fluency in technical language and organisational infrastructure. These prerequisites systematically advantage already-organised, urban, educated actors while marginalising those with lived cancer experience but without organisational affiliation, rural populations, and lower socioeconomic groups (28). The issue of representativeness is raised by this, with questions of who participates in formal structures and whether they represent the full social and territorial diversity affected by cancer.

Given this scenario, the professionalisation of the organisations stands out as an opportunity to increase the validation and consequent participation of the organisations in high-level decisions related to cancer, as it is also emphasised in international literature to ensure a high impact of organisations (56). This is relevant since civil society representatives express that

they currently have little influence in decision-making, despite their experiential and contextual knowledge. This aligns with the literature that indicates that participatory instances are not enough if a meaningful and effective participation is not assured (3,20,57).

Professionalisation is also important when representativeness and legitimacy are further complicated by the relationships between patient organisations and the pharmaceutical industry. As part of the broader commercial determinants of health, industry influence is exerted through the funding of organisations, which creates potential conflicts between commercial and public health objectives (58,59). As participants noted, these relationships raise suspicions that organisations may be "captured by industry," which further complicates validation of civil society as legitimate actors. Addressing this requires regulatory frameworks with mandatory disclosure of funding sources, clear declaration of conflicts of interest, and governance structures ensuring organisational independence in policy advocacy (60).

These power differentials can lead to conflictive situations within decision-making circles, in which the results suggest that the approach to conflict is incipient and mainly avoidant. In this regard, academics can play an essential role in mediating or facilitating conversations or, according to the literature, creating participation programs that anticipate and manage conflict to strengthen social participation in health (13,50). In this line, the importance of sustaining instances of dialogue becomes evident through a conception of participation as a process and not confined to specific projects delimited in time, given that, as established in the national literature, participation is characterised as reactive to the shortcomings of the health system or the policies that support it (37). This would contribute to the knowledge of

different perspectives on the disease and the experiences of patients and their families, and enable a resignification of the view of cancer beyond the biomedical approach.

In relation to these dynamics, the findings suggest 'participation fatigue', the exhaustion and disengagement that occurs when participatory processes demand sustained effort without producing tangible results (61). Several participants noted that citizens are disillusioned because processes are not sustained over time and they perceive no progress on their needs. Addressing this requires clear accountability structures showing how civil society input influences outcomes, feedback on what has been done with contributions, and institutional commitment that transcends individual political administrations (62,63).

The identified barriers have also been documented internationally. One study, based on experience in Portugal, describes the challenges of coordinating with community and institutional stakeholders when developing a municipal health strategy, as well as the constraints on decision-making power. The study highlights that formal mechanisms do not necessarily guarantee meaningful influence (64). Similarly, the Brazilian experience with health councils shows that even well-established participatory structures can struggle to sustain community engagement, avoid bureaucratisation and influence policy decisions effectively (65). Although these studies occur in different governance and health system contexts, their findings resonate with the barriers identified in the Chilean case, suggesting that fragmentation, limited influence and institutional constraints are recurrent issues in participatory health governance across settings.

Addressing these challenges requires concrete, multi-dimensional supports. Recent international guidance identifies key facilitators including capacity strengthening, adequate public resources, health literacy training, financial and non-financial compensation,

accessible information formats, material supports such as transportation and childcare, and sustained institutional commitment beyond individual projects (66). These facilitators address not only technical barriers but the structural inequities that determine who can participate meaningfully in health decision-making.

It is important to emphasise that the identified barriers are rooted in broader structural and relational dynamics. Social participation is shaped by the interaction between different actors and groups depending on their relative power, organisational trajectories, ideological orientations and access to information (67). Participation must therefore be understood as a historically and culturally situated process influenced by institutional configurations and symbolic structures that determine who is considered a legitimate interlocutor and which forms of knowledge are validated. Therefore, overcoming polarising and technocratic approaches to participation requires establishing connections that bridge the gap between civil society and health authorities, such as sustained dialogue and collaborative practices that redistribute power and recognise plural epistemologies.

In terms of the strengths and limitations of this study, a key strength lies in exploring the experiences and perspectives of the various stakeholders involved in decision-making processes. This provides a comprehensive understanding of an area where diverse interests converge (68). Although the results focus on the barriers to participation in decision-making, it is also relevant to mention that the interviewees highlight the significant progress made in the country in this area, particularly in the field of cancer. This refers to the development of concrete mechanisms for citizen participation in health. Examples include the establishment of the National Cancer Commission, Health Users' Councils and Public Health Consultative Councils, which are linked to Primary Health Care (PHC). These bodies are intended to

institutionalise social dialogue and enable the population to influence health planning and evaluation (37).

It is important to note that there are some significant limitations. First, there is a relative overrepresentation of organisations from the central macro-zone compared to the northern and southern macro-zones. This is partially because a large part of the national health policy decision-making activities are centralised in the central macro-zone. Future research may delve deeper into the territorial differences in social participation in cancer according to the particular needs in those places.

Secondly, the study examined how formal participatory mechanisms function within Chile's cancer policy framework by focusing specifically on organised civil society, academics, decision-makers and politicians. While this focus was intentional and necessary in order to understand institutionalised participation, it meant that the perspectives of individuals with cancer experience who are not organised and remain outside of formal advocacy structures were not captured. Future research should complement studies of formal participation by including the views of non-organised citizens and patients.

Thirdly, our sample selection did not explicitly incorporate an equity-focused sampling strategy. Participants involved in the National Cancer Plan and Law processes were prioritised over ensuring representation of social groups bearing a disproportionate cancer burden, such as lower socioeconomic populations, rural communities and specific demographic groups with a documented higher prevalence and mortality rate of cancer. This reflects a broader tension in participatory research: individuals who are already involved in formal mechanisms are more accessible to researchers, which could perpetuate the same

barriers to representation that our study criticises. Future studies should therefore develop intentional, equity-focused recruitment strategies.

CONCLUSIONS

This study investigated the perception of different stakeholders regarding the role of organised civil society in health policy decision-making concerning the National Cancer Plan and the National Cancer Law. The results suggest that, despite significant advances in establishing formal participatory mechanisms, effective social participation in cancer health decision-making faces several barriers.

The prevalence of the biomedical-clinical vision, expressed in the asymmetries of power generated in interactions among different actors, reflects what recent literature terms epistemic injustice: the systematic devaluation of experiential knowledge from organisations in favor of clinical and academic expertise. It is crucial to recognise this knowledge, as it can improve the quality of life and experience for patients and their families, and transform the narrative around cancer and its social implications. However, experiential knowledge must carry real weight in decision-making, not just be symbolically included.

The perceived barriers, opportunities and recommendations that emerge emphasise the need for concrete support to enable equitable participation, such as capacity strengthening, health literacy training and accessible information. They also emphasise the need for transparent governance frameworks to manage relationships with the pharmaceutical industry and accountability structures that address participation fatigue by demonstrating how civil society input genuinely influences outcomes. This requires building trust between the authorities and civil society, redistributing decision-making power and establishing sustained mechanisms for diverse civil society representation. In this way, the work developed by civil society,

academics, politicians and decision-makers could transcend individual leaders and governments, ensuring that work is based on long-term objectives grounded in equity and epistemic justice in Chile.

Table 1. Study participants.

Participant code	Gender	Macrozone of residence	Educational level	Main activities	National Registry of Health-related Organisations
Civil society organisations (n=16)					
E1, Registered organisation	Male	Center	Higher education	Policy advocacy, educational activities	Yes
E2, Registered organisation	Male	Center	Higher education	Policy advocacy, educational activities	Yes
E3, Registered organisation	Male	Center	Higher education	Policy advocacy, educational activities	Yes
E4, Registered organisation	Female	South	Higher education	Policy advocacy, educational activities, research collaboration	Yes
E5, Registered organisation	Female	Center	Higher education	Policy advocacy, educational activities	Yes
E6, Registered organisation	Female	Center	Higher education	Policy advocacy, educational activities, research collaboration	Yes
E7, Registered organisation	Female	South	Higher education	Policy advocacy, educational activities	Yes
E8, Registered organisation	Female	North	Higher education	Policy advocacy, educational activities	Yes
E9, Registered organisation	Female	Center	Higher education	Policy advocacy, educational activities	Yes
E10, Registered organisation	Female	South	Higher education	Policy advocacy, educational activities	Yes
E1, Unregistered organisation	Female	Center	Secondary education	Direct patient support, educational activities	No
E2, Unregistered organisation	Female	South	Secondary education	Direct patient support, community organizing	No
E3, Unregistered organisation	Female	North	Higher education	Direct patient support, community organizing, rehabilitation activities	No
E4, Unregistered organisation	Female	Center	Higher education	Policy advocacy, educational activities	No
E5, Unregistered organisation	Female	North	Secondary education	Direct patient support, community organizing, rehabilitation activities	No
E6, Unregistered organisation	Female	North	Higher education	Policy advocacy, educational activities	No
Health decision-making authorities (n=5)					

E1, Decision-maker	Male	South	Higher education	Public health administration	-
E2, Decision-maker	Male	South	Higher education	Health system governance	-
E3, Decision-maker	Female	North	Higher education	Public health administration	-
E4, Decision-maker	Male	Center	Higher education	Public health administration	-
E5, Decision-maker	Female	Center	Higher education	Public health administration	
Politicians (n=3)					
E1, Politician	Female	Center	Higher education	Legislation, health policy advocacy	-
E2, Politician	Female	Center	Higher education	Congressional representative	-
E3, Politician	Female	South	Higher education	Legislation	-
Academics (n=4)					
E1, Academic	Male	Center	Higher education	Research, teaching, policy advisory	-
E2, Academic	Female	International	Higher education	Research, teaching, policy advisory	-
E3, Academic	Male	Center	Higher education	Research, teaching, policy advisory	-
E4, Academic	Female	Center	Higher education	Research, teaching, policy advisory	-
Total participants n=28					

Table 2. Barriers, opportunities and recommendations for participation.

Barriers	Opportunities	Recommendations
Organisation of civil society	Promote joint and articulated work between organisations	Establishment of work instances with organisations from all macro-zones of the country.
		Gathering of information from civil society to generate projects.
Lack of validation of organisations in the decision-making process	Register of organisations	Assistance in the formalisation and professionalisation of new groups.
	Training	Training in advocacy, ethics and health system.

and Professionalisation of civil society organisations	Research	To make visible the contribution of civil society groups to public policies.
	Conversation instances between organisations and authorities	Guided by academics to exchange proposals.
	Relationship with the pharmaceutical industry	Establishment of a regulatory framework for good practices and transparency.
Access to information	Dissemination of advances of the National Cancer Law	Development of a decentralised strategic line of citizen participation in the National Cancer Plan.
	Strengthening the National Cancer Commission's articulating role	To promote fieldwork of the members of the National Cancer Commission.

List of abbreviations

NCP: National Cancer Plan

NCL: National Cancer Law

NCC: National Cancer Commission

NRO: National Registry of Health-related Organisations

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DECLARATIONS

Ethics approval and consent to participate

The study was approved by the Comité Ético Científico de la Facultad de Medicina Clínica Alemana Universidad del Desarrollo (number 2023-60).

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

Consent for publication

Not applicable.

Availability of data and materials

The data supporting this study's findings are available on request from the corresponding authors, A.O. and B.C. However, the data are not publicly available because they contain information that could compromise research participant privacy/consent.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

BC, AO, FV, CC, AR and ME contributed to the study's conception and design, data acquisition, analysis, and interpretation. FV and AR drafted the work, and AO, BC, CC, and ME substantively revised it. All the authors read and approved the final manuscript.

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